

# Health Education for Heart Patients in Crisis

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THE CRISIS of a myocardial infarction, the threat of recurrence and death, and the impact of prescribed changes in living patterns on the patient and his family are not being dealt with adequately in most hospital settings. Although the hospital setting is structured, staff-patient and staff-family interaction is unstructured and ambiguous in the sense that there is no systematic provision for emotional support and assistance in coping with the crisis.

The staff's view of what information and support are needed by the patient is sometimes

uncoordinated and may be based on professional and scientific understanding of the problem. Therefore, the information provided for the patient may increase his anxiety about the present and future and diminish his ability or willingness to adopt the behaviors prescribed as essential to recovery.

Recently, the Kaiser-Permanente Health Education Center in Oakland, Calif., has developed education programs for patients with chronic conditions. The center is a unique educational resource which is part of the Kaiser Foundation Medical Care Program, a prepaid group health plan serving subscribers and their families in northern California. In 1969, the Health Education Center conducted an exploratory study of myocardial infarction (M.I.) patients and their families to assess educational needs.

A preliminary study of patients and their spouses after release from the Kaiser Foundation Hospital in Oakland suggested a need to investi-

gate the patient's experience during hospitalization (1). Therefore, during the summer and fall of 1971, a series of observations and interviews in the same hospital was undertaken with M.I. patients and their spouses. The 1969 and 1971 studies were joint efforts of the Health Education Center and the Doctoral Research Training Project in Health Education, School of Public Health, University of California at Berkeley; both studies sought data that would be useful in developing an education program.

The information gathered in 1971 is presented here in terms of educational program applications involving M.I. patients, their families, and staff. This study was done in a manner designed to generate clues to patient needs that might be the basis for developing both the process and content of education-information programs for M.I. patients in the hospital and subsequent to discharge.

### Methodology

A qualitative or field research approach was taken which emphasized in-depth interviewing, observation, and review of documents and previously gathered interview data.

I interviewed 13 patients one or more times in the hospital and, in some cases, also at home. The wives of three of these patients were interviewed separately, and close family members of four others were interviewed together with the patient. I carried on intensive observations of the coronary care unit for 2 weeks and made further field notes on brief visits during the following month. Data from lengthy home interviews for 22 additional patients and their spouses were available from the study done by Britt and van Parijs (1). An interview with five couples from that study was conducted in a group setting in 1971. The interview was 1 to 2 years after these patients had had a heart attack.

The medical records of all patients who were interviewed (and of others who were being cared for in the coronary unit while I was an observer) were reviewed for behavioral data. I also reviewed physicians' and nurses' notes which indicated opinions of the patient's adjustment to the M.I., hospitalization, and regimen and the notes which documented what the patient or his family actually did or said.

In analyzing these data I sought recurring

themes that suggested the nature of the processes whereby, and the contexts in which, the person who has had an M.I. must make the transition from perceiving himself as well to understanding himself as having a chronic illness, with all that that may mean in a reordering of life's priorities for himself and his family. Complete demographic data such as sex, age, marital status, and occupation are not included here since they were not variables of interest.

### Findings and Recommendations

Because I have chosen to discuss the findings in terms of their implications for program planning, each of the following sections focuses on a particular area of need. Some of these needs bear directly upon staff-patient and staff-family interaction, and others are structural factors which affect the relationships among staff members and consequently, their potential as patient educators. One section is devoted exclusively to patients' families, especially the spouses. But, their needs are recognized in other sections, since they must deal with the problems the patient faces, albeit from a different perspective.

*An education program should begin while the patient is in the hospital and its primary goal should be to reduce his anxiety.* Patients probe various information sources to answer questions which trouble them. Some patients and families show remarkable ingenuity and skill in securing what they need to know. They employ a variety of strategies besides direct questioning—attributing subtle meaning to what the staff members say and do and asking questions indirectly. For example, one patient told me that she had asked her physician about returning to work. His answer, "approximately 6 months," gave her important information: "That's how I found out that he thought I could care for myself in the future."

These data-gathering activities often begin very early, even during the acute care phase; they intensify during times of stress such as the transfer from the security of constant monitoring in the coronary care unit to the relative lack of attention of the general ward and the discharge to the home.

There was a consensus among the five couples interviewed as a group that there should be more direct channels of information and reassurance during all stages of hospitalization and the pa-

tient's subsequent recuperative career. In the following excerpt from the group interview the value of anticipatory guidance and peer counseling is noted.

**Mr. B:** People wonder if their concerns are normal. Someone might help you by letting you know that he went through the same stages . . .

**Mr. N:** I think I see what you're driving at, and yes, now that you mention it, it would help.

**Mrs. D.:** Explaining how you feel.

**Mr. N:** Right. You're going to feel thus and so, you're going to be concerned . . . Don't be too concerned, because things take their natural course . . . I think that would be important.

**Mrs. D:** Because I didn't know—you probably had the same feeling, you don't know how you feel. You get cold, and you don't know why you're cold.

One of Britt and van Parijs' conclusions from their earlier home interviews (1) was based upon an evaluation of the patient's knowledge retention months after discharge from the hospital.

. . . the cycle of receptivity to education is very low during hospitalization in terms of . . . [the patient's] obtaining a complete understanding of his condition and regimen. Information given during intensive care appears to be completely blocked out despite deliberate efforts on the part of the nursing staff to inform the patient about his condition.

These researchers do not acknowledge the effect on the patient's anxiety of insufficient information about where he stands and what he can do in the future. In my interviews with hospitalized patients a number of them talked about what their physicians and other staff had told them about their conditions and how fearful they felt.

Mathews (2) also found that the first phase of an educational program may need to be the reduction of anxiety, which is sometimes a barrier to receptivity: "If a patient's anxieties and problems are increased rather than decreased during his stay in a hospital, his recovery and his learning are likely to be delayed."

*Patients and spouses need help in dealing with their search for the cause of the M.I.* Patients search for the cause of their heart attacks in an attempt to rationalize what often seems to them to be capricious and undeserved. They speak of being "struck down without warning." "You're shot down at one crack." Having established a cause helps them exert control over the future, reducing the threat of a recurrence.

For someone who has thought of himself as

being "good," that is, "not smoking, drinking, or overeating," the M.I. can seem unjust. Such patients may have difficulty seeing themselves as heart patients. "I thought people who had heart attacks were fat . . . I have never smoked nor touched alcohol; I thought those things gave you a heart attack." Close to this category are patients who, for one reason or another, have already been following regimens that are similar to those prescribed for recuperating heart patients—the man who had been jogging for years and the woman who had been "taking it easy" because of having diabetes. The former adjusted to the M.I. (with his physician's help) by coming to believe that his physical fitness probably saved his life; the latter is still unsure that "taking it easy" will make a difference in her future. Other patients who had had heart attacks previously see their past adherence to their regimens as having helped them, delaying a recurrence and saving their lives.

In seeking a reason for their M.I. some patients focus on an event within close temporal proximity of the attack. This tactic can relieve anxiety about the future if the circumstance is amenable to change. However, the "cause" may be entirely spurious; for example, one patient attributed her attack to a tunafish sandwich eaten at lunch on the afternoon of the M.I. In this instance, the patient might stop eating tunafish sandwiches but continue to smoke.

Increased anxiety may result if the event the patient connects with the heart attack symbolizes or represents a pervasive unhappiness or conflict which dominates his life. A patient who found retirement a more stressful adjustment than anything in his life conveyed a sense of isolation that bordered on bereavement: "Those guys [his former co-workers] were my only friends." Another patient who sees her more recent M.I. as related to grief and loneliness since her husband's death now says, "There was no reason for me to have had the heart attack 7 years ago. I was happy then, and we never had any problems between us."

The feelings patients reveal and the context in which they discuss the cause they have assigned offer important clues for counseling. Such clues may only help the staff member to show greater understanding of the patient and his response to the M.I., since some of these life conditions cannot be controlled by the staff.

Spouses and other family members also need to answer "Why did this happen?" For example, one man chose smoking as the sole cause of his M.I. because of his physician's emphasis on it as a major factor and because the patient thought he could stop smoking. But his wife described a whole pattern of her husband's behavior related to dealing with stress, frustration, and anger, and it seemed to her that their established modes of marital communication and interaction increased his tension and intensified high-risk behaviors—smoking and overeating. The wife also felt considerable guilt about having nagged her husband. She lacks faith that the patient will change his habits, and she is frustrated and uncertain about what role to play in supporting and encouraging him to follow his regimen. This kind of conflict can be a further barrier to communication when the patient is in greatest need of support—when he has lapsed into old habits.

Patients and spouses should be helped to develop an accurate understanding of the causes of heart attacks and the etiology of coronary heart disease. The healing process should be explained along with what can be done to reduce risk of a recurrence. The burden of reminding or policing the patient who does not follow the regimen may be reduced by giving the couple a plan for recovery with some specific, agreed upon behaviors which will support the regimen prescribed by the physician. This should be developed with the concurrence of all of the parties concerned. Some couples whose communication patterns interfere with the patient's following his regimen may need extended counseling.

*Some patients need help accepting themselves as heart patients.* This is a necessary first step toward behavior change, as has long been understood by organizations such as Alcoholics Anonymous.

The "silent" or ambiguous M.I. does not fit most laymen's stereotypes of the experience of having a heart attack. One woman who had chest and shoulder pains for 2 weeks preceding her admission to the hospital asserted that she could not believe she had an M.I., and during her stay in the coronary care unit she "felt fine all the time."

The lack of obvious symptoms which he associates with heart disease may make it difficult for the patient to see his illness as requiring strict

adherence to diet, rest, and so forth, particularly immediately after returning home. This situation suggests a special need for information about what happened to his heart, with attention given to why he did not experience painful symptoms. All patients need to learn to recognize warning signals.

Another sort of patient refuses to acknowledge or even overcompensates for the diminished capacity associated with recuperation from a heart attack. Such patients may be identified by denying statements or behaviors—physical exertion too early in the recovery phase or refusal to believe the diagnosis in the face of clear signs. They should not be pushed too hard to accept their new identity. Their unadmitted fears are probably acute. Rather, they should be encouraged to express their anxieties. This may be an extended process, which only begins in the hospital.

*There is a general need for educational approaches which respect the patient's sense of timing and readiness to deal with the reality of the M. I. and the changes he will have to make in his lifestyle.* This was highlighted in the group interview.

**Mr. G:** Some people catch on faster than others, and some people have to come gradually around, like myself, you know, people who are fearful.

Some patients did not want to talk about their heart attacks, at least while in the hospital. One was not ready for a long time.

**Mr. G:** It is important though not to come in too soon, because there was a time after mine [M.I.] when I didn't want to talk about it—I wanted it kind of held off from me, I believe, but then there got to be a time when I really did want to hear.

**Interviewer:** How soon is too soon? When you were home?

**Mr. G:** I think that with me within the first year. I got my courage back after the first year—still getting it back.

This man indicated, however, that he sought out written material right away.

Another patient who rejected personal communication was reading "The Hurricane Years," a novel about a man who has had a heart attack, while he was in the general ward. He expressed a desire for other books and pamphlets at that time.

Many patients want personal communication

as well as written material about their illnesses right away. Spouses and other family members also seem to prefer having information as soon as possible from those who are involved with the patient and from pamphlets, films, and other sources. Of course, their needs differ too.

One way to allow the patient to proceed according to his own perception of need would be through written materials and letting him know someone was available to answer questions, perhaps by telephone.

The M.I. patient and his spouse might be given a packet of information, the contents of which they select with the assistance of the physician and the nurses. This would essentially be literature explaining heart attacks, heart diseases, and the healing process, and giving advice on stopping smoking and changing eating patterns. The packet should also include a list of resources within the hospital system and the community, with descriptions of the kinds of questions that could be offered, and their availability. Resources that patients and their spouses cited as important are smoking cessation and weight reduction groups, nutrition counseling, and relevant literature; assistance in finding household help; and a place to telephone for medical information when their physician is not available.

**Mr. N:** The suggestion about a central place to call in at any time, day or night, I think, is a question worth considering. For people, once they leave the hospital, begin to have questions which they can't talk to their internist about because it's night for example?

**Mr. Y:** [This] would put people with heart conditions at ease . . . just to know that this information is there.

**Mrs. D:** Especially at night when you can't sleep and all those things go through your mind—it's nice to have a telephone there and somebody at the other end who can be calm.

*Patients and their families need special reassurance at the time of discharge from the hospital.* They may view this event as threatening rather than as a sign of progress toward recovery. As stated by Britt and Keranen in a paper based upon the 1969 study (3):

[After discharge] the rest of living, adjusting, setting new priorities, learning new activities and diets, unlearning old habits, was essentially up to the patient [and his family]. What a task to face when he had for weeks relinquished his clothing . . . his job and his self-direction to others, even settling for the reduction of his identity to a simple plastic bracelet!

Going home is a shock to the patient even though he may look forward to it and feel he would be happier there. As one patient put it, "I was surprised when they sent me home with no medicine or anything else . . ." Those who are past this period recall the first weeks at home as being very difficult. One patient said:

It's an adjustment—everything is an adjustment. I don't think I realized I was that sick until I got home either, because in the hospital you have a nurse or doctor or somebody around—and then there was the medicine. But when you get home you're really alone, and you find you can't do what you used to do.

Just before discharge the physician should review the recovery plan suggested previously, making it as clear and specific as possible. Both patients and their families should be prepared for physical symptoms that are not serious but which might make them uneasy; they should be told what symptoms should be reported. Patients need reassurance that their possible anxiety during the first days at home is normal. Former patients (see below) can provide extra support at this time.

*Patients should have an organized opportunity to receive support and guidance from former patients.* The overwhelming impression from the group interview was that patients sought out one another; there seemed to be an immediate bond between them, arising from their common experience. They said that they would like to have someone to talk with who personally understands their situation.

**Mr. Y:** If there'd been somebody I could talk to, that had been along that route before, I think I could have gotten some confidence from them . . . it takes someone who can speak from experience.

Spouses, too, thought it would help them to talk to others who had had the same experience.

Organized peer support and counseling have been successful in a variety of situations. For example, the American Cancer Society sends selected people who have passed through the crisis of a mastectomy or a colostomy to visit new patients in the hospital. Since the spring of 1972 a pilot program of heart patient volunteers has been in operation at Kaiser-Permanente Medical Center in Oakland under the joint sponsorship of the local Heart Association affiliate. These volunteers see patients in the hospital and at home. They offer the three modes of help which Silver-

man describes as the functions of helping widows in a "widow-to-widow" program: "She provides support, is a role model, and is a bridge person" (4).

*The families of M.I. patients should be included in an education program.* Seeing a loved one in the coronary care unit may cause great fear and upset, which the visitor may communicate to the patient. The machinery can seem very impersonal and threatening to some; for others, it may be reassuring that the patient is receiving "the best that medicine can offer." In either case, they need to know that changes on the monitor while they are visiting the patient are being observed by the nursing staff, who know how to recognize danger signals, and also that the activity of a visit will normally cause changes which are not dangerous to the patient. At Kaiser-Permanente, families of patients are usually given copies of written regulations of the coronary care unit. In addition, they should have access to audiovisual or written communications describing the evolutionary process of coronary heart disease and patient care. As I have said previously, the family members need personal contact, explanation, and reassurance; staff members should be sensitive to this need; and time should be allotted to fill it. The peer counseling program could begin during the anxious hours spent in the waiting room.

Some patients have recommended that spouses be allowed to stay with the patient for long periods of time in the coronary care unit when it is appropriate. This is already an informal practice, but the informality may penalize people who are reluctant to ask for exceptions to the rules.

A spouse or other close family member may have anxieties or needs for information as great as the patient's. And, these needs may affect that person's ability to help the patient. One wife who, in the past, was unable to influence successfully her husband's health habits expressed concern about what to do to reduce his future risk. She said, "I'll never nag him again, but how can I get him to stop smoking or lose weight?" Another wife asked, "How do I take care of him so that it won't happen again?" One man described this dilemma very well: "I think a wife is in a perilous role there [telling her husband to stop smoking] . . . she wants to be helpful. She doesn't want to see you do these things and you know that . . . but—"

The staff needs to consider the roles they want the spouses to play and what assistance they can give a family member that will help the patient to adjust to his condition and follow the recommended regimens.

One conclusion from the 1969-70 study was (1):

Families can play a significant role in the care of the patient after he is discharged from the hospital, yet there is little evidence that providers of medical care either use this resource or even encourage it.

*There is a need for a mechanism to assure systematic exchange of information among hospital staff members.* A patient's expression of concern about some aspect of his condition or his future may be tentative and uncertain as he tries to understand the meaning of his heart attack. With one staff member he may feel a need to show confidence while, with another, he may express his fears. This may, in part, reflect a sense of his past self-identity or his accustomed presentation of himself as a person. To take a single example, Mr. K. had expressed to me considerable confidence that his employer had assured him that he had all the time he needed to recover and gradually return to full-time work. However, 3 days after the interview, a chance conversation with an intern in the ward revealed that Mr. K. was indeed very upset about the possibility of losing his job. This physician was caring for the patient's roommate, another M.I. patient. Mr. K. had interrupted the physician and the other man on several occasions to talk about his employment. "What do you think they will do to me; will they fire me?"

In the coronary care unit, considerable information is exchanged informally because of the relatively small caseload and the special status accorded the coronary care unit nurses by staff physicians and interns. However, some physicians rarely interact with the nurses except to leave orders.

In the general ward, because of the larger caseload and traffic and congestion at the nursing station, there is far more reliance on written communication; that is, the "nurse's record" and the "doctor's remarks." In the ward, as well as the coronary care unit, there is a transfer of certain information among nursing shifts through the report sessions.

A remedy for the inconsistency of staff communication about patients would be a document

which contains comments and information by various staff members and the questions and concerns expressed by patients and their families. As a part of the patient's medical record, such a document could be of great assistance in planning an education program for him, and it could also help the staff in performing their regular functions.

However, there is no substitute for the individual sensitivity and ability to relate well to the patient. As Palisin noted in her criticism of nursing care plans (5), "It has become very fashionable to pick up cues, assess, and plan, all this without getting validation from the patient himself about what is going on with him," and from her observations she concludes:

Nurses who tended to give highly individualized care were usually unfamiliar with the care plan because they knew that the patient's needs and expectations varied from day to day, and even their relationship with given patients would vary within an eight-hour shift. Their interactions and planning were more individualized precisely because they could be more spontaneous. That, I believe is the key to better patient care.

*Insofar as possible what the individual physician has in mind for the patient should be made clear to the rest of the staff members.* As de la Vega notes (6): "It is . . . necessary for communication between team members to flow smoothly so that conflicting instructions to the patient are avoided." Nurses feel that they cannot give patients specific information about their condition or future because physicians differ, and the nurses fear saying something counter to what the physician has said or would say.

A resident with the cardiovascular service explained that variations from physician to physician regarding the patient are a problem for an educational program. The physician himself is often uncertain about the patient's future prospects.

Within these constraints there are, nonetheless, specific items of information which a doctor could select for his patient and relay to other staff members. The physician might be given a checklist—"needs to know about sexual activity," "needs to have information about heart attacks and coronary heart diseases," and so on.

## Conclusion

A heart patient tends to describe himself as being a "different person" after the M.I. As stated by Clausen (7):

If a man often creates his own opportunities and imposes his own definitions on situations, he must also, at times, adopt changes in his ability to control his own destiny. Permanent disability, infirmity of old age, failure in a salient role—all these pose problems for the individual's identity. He must come to terms with the fact that he is not something he was, something to which he was committed.

When the patient feels he is unable to do things which will help him control his future, anxiety is likely to be increased. He may then find it more difficult to behave in a way consistent with his physician's advice. And, a physician's recommendation may seem arbitrary if it is made without the patient's participation and if it does not take into account his unique needs and lifestyle. The meaning of "taking it easy" can be quite different for a young man with a family than for an elderly widow living alone. The physician needs the patient's input about what is possible for him and what he values in life.

Finally, patients should be brought into fuller partnership and participation in their own care. In earlier sections I have pointed out patients' considerable skills and motivation which are apparently not fully recognized and are underutilized by the providers of medical care. Family members, too, are important allies. An education program would help to increase the effectiveness of both patients and their families in the total scheme of recovery and risk reduction.

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